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ALBERTA HUMAN TISSUE PROCUREMENT TASK FORCE

FEB 14 1985
EDMONTON

ANNUAL REPORT

1983/84

Chairman

Mr. A. Little

Members

Dr. J. C. Butt
Dr. P. C. Craigie
Mr. John Dahl
Dr. John Dossetor
Dr. D.T.R. Hassard
Dr. John Klassen
Dr. William Lakey
Ms. Joan Nightingale

Research Coordinator

Ms. Denise Dunn

Recording Secretary

Ms. Flo Gorai

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PART I

INTRODUCTION: EARLY ACTIVITIES

The Alberta Human Tissue Procurement Task Force was established by the Minister of Hospitals and Medical Care by Ministerial Order #33/82 pursuant to Section 5 of the Department of Hospitals and Medical Care Act. The purpose of the Task Force was to make recommendations to the Minister in connection with the planning of more effective means for the procurement and utilization of human organs and tissues throughout the Province of Alberta. The specific Revised Terms of Reference of the Task Force are contained in Ministerial Order #31/83 and appear as Appendix A to this report.

The establishment of the Alberta Human Tissue Procurement Task Force arose out of a private motion put before the Legislative Assembly by Mr. Andrew Little who was, at that time, the representative for the riding of Calgary-McCall. The motion received wide support in the house and, on September 10, 1982, the Task Force was established. The first organizational meeting was held October 13, 1982.

During the early months of its existence, the Task Force spent a considerable amount of time informing itself as to the current status of organ procurement and transplantation within the province. Representatives of specific interest groups in the area were invited to attend the Task Force meetings and outline their particular group's position. In this regard, the Task Force heard representations by Mrs. Mae Cox, Executive Director, Organ Donors Canada, Mrs. Madeline De Hammel, Supervisor of Eye Services, Alberta Division, CNIB, and Dr. J. M. Turc, Canadian Red Cross. In addition, the Task Force invited Mrs. Ann Russell, Legislative Planner, Social Services and Community Health, to make a presentation on current related legislation, its strengths and weaknesses.

From its earliest days the Task Force has taken a keen interest in the existing transplantation coordination programs currently set up under the name of HOPE programs at the Foothills Provincial General Hospital and University of Alberta Hospitals. A sub-committee of the Task Force was struck with the specific purpose of studying the HOPE Program.

PART II

TASK FORCE ACTIVITIES, 1983/84

1. Public Opinion Poll

At the March 1983 meeting of the Task Force, a motion was passed to the effect that the Task Force was to take immediate action to solicit written submissions about public concerns on organ procurement. With the assistance of personnel from Francis, William and Johnson Ltd., an advertisement was devised. The advertisement posed the following questions:

(1) Where do you stand on the subject of organ and tissue transplants?

(2) Should the decision to donate or not be mandatory or voluntary?

(3) Should next-of-kin have the right to alter a donor's wishes?

(4) Should the driver's licence donor card system be replaced by a computer bank? How should the new system operate?

The advertisement was submitted for Ministerial and Departmental approval and was then placed in the daily, religious and ethnic newspapers published throughout the province on September 9, 1983.

As at the date of writing, individual responses to the newspaper advertisement were not overwhelming, at least in terms of numbers. On the other hand, it should be noted that those individuals who did take the trouble to respond, for the most part, provided extremely thoughtful opinions. An analysis of the responses received revealed a significant consistency between all those individuals responding and left the Task Force with the impression that, at present, tissue donation and transplantation is not a particularly controversial subject in Alberta. Appendix B provides a brief synopsis of the responses received.

Certain special interest groups were polled directly, by correspondence. In this regard, responses were received from Organ Donors Canada Limited and the Alberta Medical Association.

2. International Symposium and Possible Liaison with Dr. Calvin Stiller and the Task Force for Kidney Donation in Ontario

At the June 8, 1983 meeting of the Task Force, the possibility of arranging a major international symposium to be held in Alberta was discussed. In due course, an overall structure for the symposium was presented by Dr. Dossetor and a location - the Chateau Lake Louise - was selected.

A symposium sub-committee consisting of Dr. Dossetor, Mr. Little, Mr. Dahl, Dr. Craigie and Miss Nightingale was struck and a planning document was presented to the Task Force. On September 2, 1983, Mr. Little, Dr. Dossetor and Dr. Craigie met with the Honourable D. J. Russell for the purpose of discussing the symposium. Mr. Russell was able to grant approval in principle only of the Task Force's plan and requested the submission of a detailed budget prior to the making of any sort of formal decision. The Task Force members agreed that, since approval in principle has been received, it was necessary to proceed with the planning of the symposium.

Present plans call for the symposium to be held May 22 through 25, 1985. Four specific areas will be discussed; ethical aspects, legal aspects, procurement and storage.

(a) Ethical Aspects of Organ/Tissue Procurement

Dr. Peter Craigie will act as Co-Chairman of a plenary session on ethical considerations in human organ procurement and exchange. Possible topics include the ethical aspects of disposal of organs after death, the ethics of live/related organ donation and the ethics of the legislative imposition of mandatory decision making on individuals with regard to their desire to donate. Among the speakers being considered for this plenary session are Dr. David Roy of Montreal, Dr. Freedman of London, Ontario, and Dr. Malcolm Muggeridge of England.

(b) Legal Aspects of Organ/Tissue Procurement

This plenary session will be co-chaired by Dr. John Butt, Chief Medical Examiner for the Province of Alberta. Possible topics will include establishing the legality of the diagnosis of brain death, legislating presumed consent in the absence of refusal to organ donation and the practicality of enforcing a donor's wishes to donate in the face of the disapproval of his or her close relatives. Possible speakers will include Mr. Bernard Dickens of the University of Toronto, Mr. Edward Keyserlingk of the Canadian Law Reform Commission and a practising barrister with experience in medical/legal issues.

(c) New Ideas and Techniques for Organ and Tissue Procurement and Exchange

This session will be chaired by Dr. John Klassen from the Foothills Provincial General Hospital transplantation team. Proposed topics include the organization of a large metropolitan tissue bank, the case for a hospital based organ procurement team in large urban areas, and the experience in the U.S.A. of harvesting corneas in different jurisdictions. Possible speakers include Mr. Gene Pierce, Chairman, Southeastern Organ Procurement Foundation, Richmond, Va., Dr. Roger Evans, Batelle Institute, Seattle, Wash., and Mr. Robert Smith of the MORE Program in Ontario.

(d) Organ Storage: Past, Present and Future

It is proposed that Dr. William Lakey chair this plenary session. Topics of discussion will likely include current status of organ preservation techniques; the American experience with tissue banking; perceived, present and future needs in Alberta and anticipated research gains in cryobiology over the next five to ten years. It is suggested that a medical doctor associated with the U.S. Navy tissue bank, Dr. J. M. Turc, from the Canadian Red Cross, and Dr. Raymond Rajotte from the University of Alberta may well be among the speakers.

Dr. Dossetor has been in contact with Dr. Calvin Stiller, Co-Chairman of the Ontario Task Force for Kidney Donation, and Chairman of the Centre for Transplant Studies at the University Hospital in London, Ontario. Dr. Stiller has advised that a local symposium is proposed for Ontario next fall and has invited the Alberta Task Force to consider forming a liaison with his group for the purposes of coordinating these symposia and otherwise exchanging information. In particular, both groups are presently collecting data on the various existing barriers to transplantation as they are perceived at the present time, and it is hoped that this exchange of information will be generally beneficial.

3. Reports by Student Research Assistants

During the summer of 1983, two university students were employed on STEP grants to assist the Task Force. The students were Clare Dossetor from the Faculty of Medicine and Diane Holowachuk from the Faculty of Law.

Ms. Dossetor's work consisted of two studies, one concerning tissue banking and the other concerning sources of medically accepted organ donors. To provide the Task Force with a preliminary study on practitioner-perceived needs for a tissue bank, Ms. Dossetor toured throughout the province discussing the matter with specialists in different transplant practices. Her report consisted of a systematic breakdown of responses into different tissue groups - skin, bone, sperm, corneas, joints, etc. Ms. Dossetor also studied the characteristics of persons seriously injured in highway traffic accidents with a view to ascertaining how many of these individuals are potential donors.

The present law in such major areas of donor consent and the desirability of a legal definition of brain death was reviewed by Ms. Diane Holowachuk. Ms. Holowachuk's investigations focused on the law in the Province of Alberta but also covered the law in other Canadian jurisdictions as well as in Great Britain and the United States.

The Task Force found the STEP student reports to be most useful and considered itself fortunate in having been able to take advantage of the STEP program.

4. Travel by Task Force Members

Various members of the Task Force had the opportunity of meeting with other transplant professionals at international conferences and otherwise.

(a) International Congress on Organ Procurement, April 14 - 16, 1983, Maastricht, The Netherlands

Task Force member, Dr. John Klassen, attended this symposium.

(b) Southeastern Organ Procurement Foundation (SEOPF), May 5 - 6, 1983, Williamsburg, Virginia

Mr. Andy Little, Chairman of the Task Force, attended a SEOPF general meeting and met with Executive Director, Gene Pierce.

(c) Meeting with U.S. Surgeon General and Other Persons Involved with the American Council on Transplantation, November 18, 1983, Washington, D.C.

Dr. John Butt travelled to Washington, D.C. and met with Dr. Everett Koop, U.S. Surgeon General. The newly formed American Council on Transplantation was discussed and Dr. Butt was given useful reference material as well as the names of involved persons in this American Federal Task Force. Dr. Koop has invited the Alberta Task Force to send a designate to the American Council on Transplantation meetings this January.

5. Alberta Society of Ophthalmologists/Alberta Eye Bank Inc.

At the April 27, 1983 meeting of the Task Force, Dr. T. Demong of the Steering Committee of the Alberta Society of Ophthalmologists, presented a brief concerning the possible establishment of an Alberta Eye Bank. This Committee has drafted recommendations regarding, not only the implementation of an independent eye bank, but also the establishment of a training program for technicians who could harvest corneas. He also intends to develop a public relations effort within the communities to increase the awareness of the need for more donor corneas. Since there is an apparent overlap of interest areas between Dr. Demong's group and the Task Force, both organizations have agreed to keep in contact so that splintering and duplication of effort can be avoided.

6. Research Coordinator

The Task Force placed advertisements in the Edmonton Journal and Calgary Herald for the position of Research Coordinator. A number of applications were received and four of these were placed on a short list and interviewed. The successful applicant eventually selected was Denise Dunn, a lawyer with background in Social Sciences and a particular interest in medical/legal matters. Miss Dunn will be carrying out a number of studies on behalf of the Task Force on a wide variety of topics including key legal issues not currently provided for in the legislation, the feasibility of tissue banking in Alberta, the typical characteristics of the average organ donor and other research projects which may be proposed by Miss Dunn or the Task Force from time to time. In addition, Miss Dunn will continue to assemble and cross reference information and will assist with the planning and implementation of the proposed international symposium.

7. Week End Retreat, November 25 - 27, 1983

The Task Force held a series of week end meetings this past November for the purpose of reviewing its progress to date, consolidating its position on present issues and determining its future course of activities.

(a) Dr. Klassen reviewed the demand for the various types of tissues and indicated that a need probably does exist for some form of unified tissue banking. It was proposed that data be collected and updated with respect to tissue demand and that each organization utilizing potentially banked tissue be further polled for information. On receipt of such information, and in light of previous studies in the area, the Task Force will be in a position to make recommendations concerning a formal tissue bank.

(b) Dr. Dossetor reported on his conversations with Dr. Stiller of the Ontario Tissue Task Force for Kidney Donation. The Ontario group has established a panel of experts to investigate perceived barriers to transplantation ranging from conditions prevalent at the time of serious accident to post-transplant costs and barriers generated by the medical profession. It was proposed that the Alberta Task Force also investigate such barriers and the following topics were agreed upon and assigned to a similar "shadow" group:

(i) Barriers at the accident scene including the donor card consent, police activities, and ambulance procedures - Andy Little.

(ii) Barriers in the emergency room related to facilities and procurement procedures - Joan Nightingale.

(iii) Barriers arising out of the diagnosis of brain death - John Butt.

(iv) Barriers existing in perfusion and processing systems - William Lakey.

(v) Barriers related to living donors, both blood related and emotionally related - John Dossetor.

(vi) Barriers arising out of failure to get full physician collaboration - Don Hassard.

(vii) Barriers arising out of post-transplant care and costs - John Klassen.

(viii) Barriers arising out of current consent law and procedure - Denise Dunn.

A schematic drawing outlining barriers to transplantation appears as Appendix C.

(c) Dr. Butt reported on his investigations into key medical/legal issues affecting organ transplantation. He advised that there are a great many areas where lack of legal clarity may well be contributing to an insufficient number of transplantations taking place. It was recommended that the Task Force investigate such areas as the regulation of tissue handling and disposal, the regulation of perfusion and tissue banking, the regulation of transportation of deceased individuals across provincial and international boundaries, and the sale of certain organs or tissues, and that recommendations for legislative reform be made to the Minister.

(d) Dr. Craigie presented the Task Force with a suggested outline for the final report of the Task Force to the Minister. He also proposed that the core of those recommendations be the creation of a transplantation council which would generally oversee all matters pertaining to organ donation, procurement and transplantation within the Province of Alberta and which would likely liaise with other provincial and national organ transplantation groups. It was proposed that the corporate and organizational structure of apparently analogous groups such as the Canadian Red Cross or the Alberta Cancer Board be studied.

The Human Organ Procurement and Exchange Program (HOPE), which is operated out of the Foothills Provincial General Hospital and University of Alberta Hospitals, was discussed at some length. The Task Force supports this program and intends to make recommendations to the Minister concerning it.

8. <u>The HOPE Program</u>

The HOPE Program began in December of 1978 when the Alberta branch of the Kidney Foundation of Canada received a grant of $50,000 from the Government of Alberta. The primary aims of the program were to coordinate the exchange of patient data between different transplant centres and handle data concerned with kidney, cornea and other organ procurement transport and perfusion and to promote the awareness of the needs of transplantations throughout the Province of Alberta by the implementation of various educational programs. The program became functional October 15, 1979 when coordinators were appointed for the City of Calgary and the City of Edmonton. These coordinators work out of the Foothills

Provincial General Hospital and the University of Alberta Hospitals. Although the program has only been operational for a few years, there is evidence that it has succeeded in achieving an increased number of cadaveric donations and transplants.

In May of 1983 the Task Force presented a series of short term proposals concerning the HOPE Program, which proposals were drawn up by the HOPE Program Sub-Committee. The Task Force has recommended that the HOPE Program be continued in essentially its present form throughout the fiscal years 1984 to 1985 and 1985 to 1986, focusing as it does on the procurement and exchange of kidneys and corneas. In addition, it was recommended that the program budget be specifically increased in the following areas:

(a) Funding for publicity and advertising addressed to the general public.

(b) Funding for new videotape programs addressed to health professionals.

(c) Funding for increased support staff.

The Task Force proposes to study the HOPE Program as it now exists and to prepare, by way of recommendation, revised terms of reference expanding the scope of its operations.

9. Proposed Involvement of Chief Medical Examiner's Office in the Obtaining of Donor Consent

Dr. Butt has advised the Task Force that his office is prepared to recommend to the Attorney General that its staff contact families of deceased individuals falling under its jurisdiction to request their consent to donation of such tissues as corneas, skin and bone. Should approval for this proposition be received, it is proposed that the Calgary office initially concentrate on one type of tissue only, with the Edmonton office initially concentrating on the other. If success is achieved, each office will expand its operations to include all types of tissue. As presently conceived, the program would be unique in Canada, but the success of similar programs in various parts of the United States, notably the state of Texas, is highly encouraging.

PART III

CONCLUSION, PROPOSED ACTIVITIES FOR 1984/85

During the next fiscal year the Task Force intends to continue its work in amassing and cataloguing information, particularly as it relates to other successful transplant programs in different parts of the world. As mentioned, there will be a continuing relationship with the Ontario Transplantation group with the possibility of mutual participation in proposed upcoming symposia. In addition, the Task Force will likely be taking advantage of the invitation extended to it by the U.S. Surgeon General and the American Council on Transplantation to participate in future meetings. Task Force members will make and maintain contact with other related groups as the opportunities arise.

The preparation for the international symposium will undoubtedly occupy a great deal of the Task Force's attentions during the next fiscal year. Speakers will be officially invited in the near future and, once the program has been finalized, publicity will begin. As proposed, the symposium will focus on a wide variety of crucial topical areas and it is anticipated that considerable interest within the medical, legal and other professions will be aroused.

The issue of the desirability of a tissue bank system for the Province of Alberta has been studied in the past, but it will be necessary for the Task Force to update its information in this area. Thus, a major study is proposed, to be carried out by the Research Coordinator, which will include an investigation into and discussion of successful operations located elsewhere. The following additional studies have been proposed to be carried out by the Research Coordinator within the next year.

(a) Donor Profile Study using data collected by the HOPE coordinators and the Chief Medical Examiner's staff. The Research Coordinator will obtain a profile of the sort of person most likely to consent to organ donation in Alberta. The results of this study will, hopefully, be of use to those doctors, nurses and others considering approaching a patient or their family with a view to seeking their consent to donation.

(b) The Legality of Enucleation of Eyes by Non-physicians. The Research Coordinator will review the law in Alberta and other North American jurisdictions in investigating the desirability of legislative revision to allow persons who are not qualified physicians to perform enucleations.

(c) The Transportation of Deceased Individuals across Provincial and National Boundaries. The Research Coordinator will review the law in this area with a view to proposing legislative revisions which would facilitate the transportation of bodies across borders for transplantation purposes.

(d) Promotional Study. The Research Coordinator will contact other North American organizations where successful campaigns securing increased organ donation have been carried out. This study will include recommendations as to the best sort of campaign for the Alberta context.

(e) Definition of Death Study. The Research Coordinator will review legislation from other jurisdictions as well as proposals by Canadian Law Reform Commissions concerning the desirability of legislating a definition of death which would include brain death. In addition, the Research Coordinator will discuss the matter with practising physicians and hospital administrators with a view to ascertaining the problems which might arise as a result of such legislation being passed.

It is anticipated that the need for studies other than those mentioned above will arise in the course of the Task Force's deliberations and these studies will also be undertaken by the Research Coordinator.

In its original mandate, the Task Force had proposed and budgeted for Public Opinion Meetings to be held in major centres throughout Alberta. While the Task Force remains resolved that it is absolutely essential that the citizens of the Province be given the opportunity to make their views known, the method and timing of this poll will be closely examined prior to implementation and may, in fact, take a form other than public opinion meetings.

PART IV

1. ALBERTA HUMAN TISSUE PROCUREMENT TASK FORCE

BUDGET

1982/83

During the fiscal year 1982/83 a sum of $2,645.00 was drawn from the unallocated portion of the budget of the Deputy Minister.

2. ALBERTA HUMAN TISSUE PROCUREMENT TASK FORCE

APPROVED BUDGET

1983/84

Regular Meetings	$10,020.00
Seminar, One Day	2,185.00
Air Fare, Mileage, Meals, Parking	8,945.00
Typing and Secretarial	2,000.00
Fact Finding Travel	10,000.00
Advertising Expense	20,000.00
Research Assistant (7 months)	17,640.00
TOTAL APPROVED BUDGET	$70,790.00

3. ALBERTA HUMAN TISSUE PROCUREMENT TASK FORCE

RECOMMENDED APPROVAL LEVEL FOR 1984/85

MEETINGS:

Assume 10 regular meetings:

10 x $490	$4,900	
10 x $105	1,050	$ 5,950
	See Note 1	

AIRFARE: 5 members x 10 meetings ($134 x 5 x 10)	6,700
CAR MILEAGE: 5 members x 10 meetings (40 km x $0.22) approximately	440
PARKING: (5 members x 10 x $7.00)	350
MEALS: (5 members x 10 meetings x $6.50)	320
RENTAL OF MEETING ROOMS for Calgary (5 meetings x $70.00) approximately	350
SECRETARIAL ASSISTANCE: Chairman	2,400
OTHER EXPENSES: Postage, stationery, long distance calls, etc. (estimated)	500
FACTFINDING TRAVEL: (members and research officer)	8,000
PUBLIC OPINION: Advertising for submission and meetings (conservatively estimated) See Note 2	40,000
MEMBERS EXPENSE for Public Opinion Meetings (Schedules II provides detailed estimate)	14,810
SALARY: Research Officer	33,180
TOTAL	$113,000

Note 1. Honoraria are estimated on the basis of 12 meetings per year with an average of 7 members and one Chairman attending each meeting.

By Order In Council #1175/80, the following honoraria are allowed:

	Members Receive	Chairman Receives	For:
(a)	$ 70.00	$135.00	Up to and including 4 hours in any one day.
(b)	$115.00	$175.00	For over 4 hours and up to 8 hours.
(c)	$185.00	$275.00	For over 8 hours per day.

Note 2. The proposed public opinion meetings are currently under re-examination to ascertain whether or not they are the most appropriate way to poll the public sentiment.

APPENDIX A

MINISTER OF HOSPITALS AND MEDICAL CARE

M.O. #31/83

WHEREAS by Ministerial Order #33/82 I established The Alberta Human Tissue Procurement Task Force pursuant to section 5 of the Department of Hospitals and Medical Care Act; and

WHEREAS the Terms of Reference have been amended;

THEREFORE, I, DAVID J. RUSSELL, Minister of Hospitals and Medical Care, pursuant to section 5 of the Department of Hospitals and Medical Care Act, hereby order that Ministerial Order #33.82 be amended by repealing the Appendix A and substituting Appendix A (Revised August 16, 1983) attached.

DATED AT EDMONTON, Alberta, this 26 day of August, A.D. 1983.

D.J. RUSSELL
MINISTER
HOSPITALS AND MEDICAL CARE

DEPUTY MINISTER

M.O. #31/83

(Revised August 16, 1983)

APPENDIX A

ALBERTA HUMAN TISSUE PROCUREMENT TASK FORCE

Terms of Reference

1 To report to the Minister of Hospitals and Medical Care in connection with the planning of more effective means for the procurement and utilization of human organs and tissue for therapeutic purposes, medical education and scientific research in the Province of Alberta and without restricting the generality of the foregoing to identify and where necessary recommend to the Minister on:

(i) key issues related to the procurement, storage and utilization of human organs and tissue,

(ii) programs related to the procurement, storage and utilization of human organs and tissue, for example, the Human Organ Procurement and Exchange Program, and the proposed Tissue Bank Facility,

(iii) levels of funding and resources required to implement the programs,

(iv) standards and operating procedures related to the procurement, storage and utilization of human organs and tissue,

(v) the legislation related to the procurement, storage and utilization of human organs and tissue,

(vi) whatever further study, research, and inquiries the Task Force deems necessary to achieve the desired results.

Membership

2 The Task Force shall be composed of nine members:

(a) Dr. John Klassen, Immunologist, member of Renal Transplant Unit, Foothills Provincial General Hospital, Calgary,

(b) Dr. John Dossetor, University of Alberta Hospital, Edmonton, member of the Transplant Team,

(c) Dr. William Lakey, Head of Urology, University of Alberta,

(d) Dr. D.T.R. Hassard, Ophthalmologist, University of Alberta,

(e) Dr. J.C. Butt, Chief Medical Examiner for the Province of Alberta,

(f) Dr. Peter C. Craigie, Dean of Humanities, University of Calgary,

(g) Mr. John Dahl, Whitecourt, Alberta,

(h) Mr. Andy Little,

(i) Miss Joan Nightingale, Department of Hospitals and Medical Care.

Chairman

3 Mr. Andy Little is designated Chairman of the Task Force effective October 13, 1982.

Term of Office

4 Members shall remain in office until July 31, 1985.

Remuneration by the Minister

5 Remuneration for members of the Task Force who are not employees of the Provincial Government or Members of the Legislative Assembly shall be in accordance with Schedule 1, Part B of the Committee Remuneration Order, being Order in Council numbered O.C. 1175/80.

6 Members of the Task Force are entitled to be paid travelling and living expenses in accordance with the Subsistence, Travel and Moving Expenses Regulation made by Order in Council numbered O.C. 293/79, as amended, or any order made in substitution therefor, as though they were employees of the Government.

APPENDIX B

From: Denise Dunn

To: Members of Alberta Human Tissue Procurement Task Force

Re: Report on Responses to Published Advertisement

As at the date of writing, a total of 37 responses to the advertisement have been received. A sample of this size is not sufficiently large for full statistical analysis, but it was felt that a general overview indicating response trends might be of assistance to the Task Force members.

Question 1: Where do you stand on the subject of organ and tissue transplants?

Not surprisingly, those persons responding to the advertisement were almost universally in favour of human tissue transplants. One writer expressed some concern about high costs and difficult ethical issues in some cases, and one writer was unwilling to make a donation herself and thus, perhaps, felt reluctant to indicate support of transplantation in general, but it appears safe to assume that Albertans are largely in favour of transplants taking place.

Question 2: Should the decision to donate or not be mandatory or voluntary?

This question appeared to have been construed in several ways by those responding to the advertisement. Generally, the respondents interpreted the question as seeking their opinion on what we generally refer to as opting out versus opting in. Approximately six of the 37 respondents appear to be in favour of the opting out system whereby consent to donate is implied in the absence of express refusal. Two respondents felt that donations should be mandatory for automobile accident victims. One favoured implied consent (opting out) in all cases of post mortem donation. One respondent interpreted the question as whether or not individuals should be forced to make a choice between donation or non-donation and took the position that the choice itself should be mandatory.

Clearly this remains a contentious area and it is probably safe to assume that the majority of Albertans would not be in favour of mandatory donation or even of implied consent to donation in the absence of express refusal.

Question 3: Should the next-of-kin have the right to alter a donor's wishes?

.../2

Only five of those individuals responding to the advertisement felt that an individual's decision to donate should be subject to alteration by relatives. The general sentiment expressed was that every individual ought to have freedom of choice to make the decision to donate and, the decision having been made, it must not be altered by any person. One respondent did feel that, where a deceased person had given no indication of their stance on donation, close relatives should have the right to make that decision for them in the event of their death.

Question 4: Should the driver's licence donor card system be replaced by a computer bank? How should the new system operate?

This question brought forth the widest variety of responses, with most people indicating that they were not overly knowledgeable in this area. Most respondents felt that the present driver's licence donor card system was a step in the right direction but that more was required. Several suggested that the present system be computerized to expedite information access. Many expressed concern over the fact that some persons may not possess or carry a driver's licence and suggested instead that donation be administered via the Alberta Health Care system with the donor cards being part of the Alberta Health Care card. Several respondents expressed concern over the possibility of computer abuse. Apparently there exists a relatively widespread belief that, were an individual's decision to be stored in a computer, that decision could be inaccurately recorded or altered by unscrupulous persons. One writer expressed concern over whether doctors and family members can be relied on to carry out their wishes while another felt that many individuals might view systematic recording of a decision to donate as likely to induce bad luck.

The majority of the respondents expressed a perceived need for much greater public education. Several pointed out that while they were in favour of transplantation and desirous of making a post mortem donation, they simply did not know how to record their wishes.

Finally, the following systems for obtaining and/or recording donations were suggested. Organ Donors Canada advocates a universal donor card system to be distributed with the Alberta Health Care card or similar document. Another respondent suggested using the yellow pages or a large advertisement soliciting donations, such advertisement to be donated by AGT. Yet another respondent suggested that the Task Force seek the involvement of various church groups throughout the province as vehicles for both public education and the encouragement of donations.

In general, the responses to the advertisement could be considered as unemotional or unheated except on one point - mandatory versus voluntary donation. It is apparent that, in some cases, even the possibility that the government might be contemplating mandatory donation was a subject of considerable alarm.

Denise J. W. Dunn

DJWD/bb

BARRIERS TO TRANSPLANTATION

TYPE OF DONOR	Organ	Technic. problems in Procurement	Technical problems in Storage: Perfn.	non-perfn short	non-perfn long	SUPPLY / DEMAND NOW	SUPPLY / DEMAND FUTURE	Problems in Organ UTILIZn.	PROBLEMS RELATING TO DIFFERENT ASPECTS: at scene of accident	in hosp. Emerg. Room	the diagnosis of brain death	the legislative aspects	M.D. collaboration	POINT OF IMPACT OF POSSIBLE REMEDIES: more H.O.P.E.	Tissue Banks	Expand role by Medical Examn.Off	Procurement Teams in Transplant Institutes
ONLY FROM LIVING DONORS	Bone-marrow	no	..	no	no	2/2	I0/I0	++ spec.unit	..	..	..	..	..	++	++	..	..
	sperm	no	..	no	no			..	..	..	..	..	..	..	++	..	..
	ova	+	..	+	+			+	..	..	..	+	..	..	++	..	..
	embryo	++	..	?	+++			++?	..	..	..	+	..	..	++?	..	..
CADAVER -decision pre-mortem & organ not transportable	Heart	+++	++	+++	++++	0/6	/I2	++	++	++	+++	?		++	?	..	+++
	Heart-lung	+++	+++	+++	++++	0/?	/?4	+++						++	?	..	+++
	Liver	++++	+++	++++	++++	0/?	/?4	++++					MS +	++	?	..	+++
-decision pre-mortem but organ is transportable	Kidney	+	+	+	++++	60/I20	I40/I40	+(+)					Neph ++	++	..	..	+++
	pancreas islets	+(+)	..	+	+	0/?	/I0?	+.						++	++	..	+++
-post-mortem decision and 6 hrs. available	Cornea	+	..	+	+++	?80/I60	I80/I80 ?	+	..	..	..	..	+	++	++	+++	+++
	Joints	+	..	..	...	0/?5	/?I5	+	..	..	..	..	..	++	++	+++	+(+)
	Bone	+	..	++	++	0/?3	/?8	+	..	..	..	..	..	+	++	+++	+(+)
	Skin	+	..	++	++												

John Dossetor, 1983